

Support groups for rare chromosome disorders in Europe meet in Luxembourg

See also: <http://www.chromosomehelpstation.com/eurochromnet.htm>

Eurochromnet is a network of European support groups for rare chromosome disorders. It began in April 2004 and is actually a virtual network. The partners in Eurochromnet decided to have the first formal meeting on Monday 20 June 2005 at the Hotel Ibis Luxembourg Aeroport. The main item of this meeting will be: continued networking in order to support families with a rare chromosome disorder in Europe.

The Hotel Ibis offers a special price for early subscribers. People need to subscribe not later than 15 April. Mrs Stefania Azzali (Ring 14) is the contact person for this. If you are interested, please contact her not later than 14 April: info@ring14.com

AGENDA - DRAFT

10.00 - 17.00 (lunch: 12.30 - 13.30), at the Hotel Ibis Luxembourg Aeroport.

1. Welcome by Beverly Searle, chair of the meeting: why this meeting?
2. Notes meeting 15 October (see Annexes Research 'United').
3. Presentation of support groups and other interested visitors.
- Also: *update of actions support groups.*
4. Update actions of Eurochromnet.
- *What happened since October 2003, by Annet van Betuw.*
5. Meet projects SAFE and Eurogentest (see also Eurochromnet Newsletter 1, January 2005).
- *By Beverly Searle and Prisca Middlemiss.*
6. Unique's Information Project: development of medically-verified, family-friendly information flyers and booklets about a wide range of rare chromosome disorders (see also Eurochromnet Newsletter 2, February 2005).
- *By Prisca Middlemiss.*
7. ECARUCA; an online database for rare chromosome aberrations.
- *By Ilse Feenstra, coordinator of Ecaruca (see: <http://www.ecaruca.net>)*
8. Discussion and agreement on next steps.
9. Involvement of researchers.
- *Discussion on participation of researchers and/or institutes in Eurochromnet.*
10. Funding issues.
11. Other business.
12. Close.

For more information you can contact:

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Chromosome Help-Station, Annet van Betuw: info@chromosomehelpstation.com

Note:

Several Eurochromnet partners will be visiting the European Conference on Rare Diseases, 21-22 June 2005 in Luxembourg.

More information: <http://www.rare-luxembourg2005.org>